

# Consent Policy Design Group

## Meeting Minutes

MEETING DATE	MEETING TIME	Location
November 12, 2019	10:00AM – 11:00AM	<b>Join Zoom Meeting:</b> <a href="https://zoom.us/j/269726549">https://zoom.us/j/269726549</a> <b>Dial:</b> +1 646 876 9923 US <b>Meeting ID:</b> 269 726 549

### DESIGN GROUP MEMBERS

Stacy Beck, RN, BSN	X	Susan Israel, MD	X	Nic Scibelli, MSW	X
Pat Checko, DrPH		Rob Rioux, MA		Rachel Rudnick, JD	X
Carrie Grey, MSIA					

### SUPPORTING LEADERSHIP

Allan Hackney, OHS		Carol Robinson, CedarBridge	X	Sheetal Shah, CedarBridge	X
Tina Kumar, OHS		Michael Matthews, CedarBridge	X	Tim Pletcher, Velatura	
Sean Fogarty, OHS		Chris Robinson, CedarBridge		Lisa Moon, Velatura	

### Minutes

	Topic	Responsible Party	Time
<b>1.</b>	<b>Welcome and Overview</b>	<b>Michael Matthews</b>	<b>10:00 AM</b>
	Michael Matthews welcomed the group and provided an overview of the agenda.		
<b>2.</b>	<b>Public Comment</b>	<b>Attendees</b>	<b>10:02 AM</b>
	There was no public comment.		
<b>3.</b>	<b>Review and Approval of Meeting Minutes</b>	<b>Attendees</b>	<b>10:05 AM</b>
	Stacy Beck created a motion to approve the meeting minutes from October 29, 2019. Rachel Rudnik seconded the motion and it was approved without objections or abstentions.		
<b>4.</b>	<b>Review of Final Report</b>	<b>Attendees</b>	<b>10:10 AM</b>
	<ul style="list-style-type: none"> <li>a. Decide on alternative language Guiding Principle 18.c., per Susan’s request;</li> <li>b. Decide on which manner to display “Other considerations”; and</li> <li>c. Approve Final Report &amp; Recommendations</li> </ul>		
	<p>Michael provided an overview of the report and said that we would discuss 3 specific items. He said that the report included a standard table of contents, acknowledgements, an introduction, and information related to members, project structure and process.</p> <p><b>Guiding Principle 1</b></p> <p>Michael said that Susan suggested to add the term “data-specific.” He believed this was a good qualifier, as the use cases will determine the different types of data available across the HIE infrastructure and platform. He asked Susan if she had any other comments and she did not. Nic said he did not have issue with the term but had issue with “data-specific” and “unambiguous” used together. He suggested “clear and data-specific.” Susan suggested to use “complete” instead of “unambiguous.” Nic said he was concerned that they may be setting a bar too high with this terminology. Susan said that the Notice of Privacy Practices are general and they do not indicate which information is shared with different groups. She is concerned that the public will not know which categories of data are being shared and with whom. Nic said that Susan is probably accurate in that consent policies are general. However, he asked the group if they want to potentially create a double standard in which the HIE is using something different compared to others in the industry. Rachel said that</p>		

“clear” and “unambiguous” say the same thing and “data-specific” does not really mean anything. She offered the terms “detailed” and “clear.” She said this terminology would ensure it is not general. Susan said she disagreed very strongly because the public would not know what data is being shared. She does not want loop holes and believed “data-specific” addresses this concern. Rachel asked what the term “data-specific” meant, as they had not defined it. Susan said her comment addresses the data categories. Nic said he is supportive with “clear and detailed”. Michael asked Susan if she would like to add any additional information to the “Other Considerations” section. Susan wanted to discuss the format of the report, as this would inform her decision. She said she is a patient privacy advocate but has been outvoted on key points in Guiding Principle 1. She would like people who read this to know there was a dissenting opinion. Her request is to leave other considerations under each guiding principle and label it as “dissenting.” Michael asked the group for their thoughts on Susan’s suggestion related to the format and display of “Other Considerations.” Nic said he did not agree with Susan. He did not believe a dissenting view should be expressed right beneath the principle. He said that if there was a dissenting view, that it should be published in the report. The group should not be making a recommendation if they did not reach a majority. He believed this should be separate. Michael asked Nic, as a compromise, if he would accept the way it was formatted on the screen. Nic said he would make this compromise. Susan asked if Nic was comfortable with labeling it as “dissenting opinions.” Nic said he would like to hear from other people. He said that Susan should be given her own section to state her position. Susan would like the body of the report to be changed, as it indicates there is consensus as opposed to a majority. Michael provided clarity on the differentiation between consensus and unanimity, which are often used synonymously but are in fact different. Michael said that consensus can be defined as “agreement by majority in sentiment or belief” or “general agreement.” He said unanimity refers to the outcome of a vote that all members agreed. He thought this was a useful perspective to bring into the conversation. He asked Rachel for her thoughts. Rachel said she did not have a strong preference. She believed it was good to have differing opinions but did not feel strongly about where they are placed. Stacy agreed with Rachel, she did not have a strong opinion and would defer to others. Rachel said she did not believe Susan’s views were “dissenting,” rather it is advocating or clarifying for more information. Susan thanked Rachel and said she is concerned that people may not click the link in the report. Susan appreciated what Michael said about consensus and asked if there was a better term to use. Susan was comfortable with “additional” considerations. Demian Fontanella, General Counsel for OHS, raised a question about the format of the report. He asked if there could be a brief paragraph under each recommendation which discussed the factors or rationale for each principle. He added that most people may look at the term “data-specific” and could think of data elements. Nic did not have an issue with Demian’s recommendation, however he would want to have a brief paragraph for every recommendation and this would require additional work. Michael said that this was his concern as well. It was a good suggestion but was concerned about adding language to the report without having another meeting for the group to review and approve. Susan said she is okay with taking out the term “data-specific”, as long as other considerations were directly underneath it. Michael confirmed that the group would like to modify the language to “clear and detailed information.” He asked Susan if she would like to modify her language in the Appendix. Susan said she would like her language to stay intact, as written. Susan asked if the Appendix will be a part of the written report. Michael confirmed. Rachel said that the title of the “Other Considerations” section did not matter from her perspective, as long as there was wording or a paragraph that explains why it was there. Michael said that they could move the introductory language in Appendix A into the body of the report. Susan said this was a good suggestion. Michael thanked Rachel for her perspective regarding the terminology.

### **Guiding Principle 9**

Michael indicated that a small edit was needed to change “when” to “what happens”. There was no objection to this change.

**Guiding Principle 18c**

Michael provided an overview of the suggested substitute language. He asked Susan if she would like to provide any further comments. She did not. Nic asked if it was appropriate for this group to use terminology about what OHS “will” do. Michael said this was a good point and that “should” could be used as substitution, since this group is making recommendations. Michael asked the group for their feedback on the substitute language. Rachel said that she did not feel well versed in OHS’s authority or structures as a state agency. She was concerned that the substituted language may weaken the guiding principles as a whole and was supportive of the original language. Nic and Stacy were also supportive of the original language. Rachel asked if Demian had any guidance or insight on this. Demian said OHS has very broad authority to hold hearings and a strong consumer engagement initiative which includes outreach efforts for the HIE and consent policies. He said OHS has the authority to take action, including promulgation of legislation. As it relates to the HIE Board, there is a bifurcated process and OHS is providing administrative support. He said the current language does not require OHS to do anything that is already required under statute. Michael reviewed the “Additional Consideration” for this principle. He asked Susan if she was comfortable changing “must” to “should” in order to stay consistent with the proposed set of recommendations. Susan said it could be changed. She also requested to make another comment. She said that one of the reasons why she thinks it is important to include this information is because the original legislation was not clear on whether patients could opt-out and which providers could have their data. She is more concerned now that it has become a non-profit and is not sure how CT law applies to this entity. Demian indicated, that because it is a bifurcated process, the bylaws of the HIE entity will comply with all applicable statutes. Furthermore, they made it a requirement that the non-profit HIE operate as a public entity as much as possible. He said that the meetings are open to the public, the public can make comment, and anything the HIE entity acts on can be directed by the Health IT Advisory Council.

Michael indicated that the group addressed all the punch list items for discussion. He would like to entertain a motion for approval of the final report which would include the changes identified on this call. Nic left the call. Stacy created a motion. Susan said, for the purpose of the minutes, she concurs but with dissent. Rachel asked for clarity on what was agreed to and what the next steps were. Michael said that the next step would be to send the final report to the Council next week with the changes discussed on the call. The changes were: adding verbiage in the body of the report about the context for additional considerations, keeping the hyperlink for “Additional Considerations”, and an Appendix in the report. Rachel seconded the motion. All were in favor, there were no abstentions or objections. Michael said that he would follow up with Nic to confirm that he accepts the recommendation as approved.

<b>6.</b>	<b>Wrap Up and Meeting Adjournment</b>	<b>Michael Matthews</b>	<b>11:25 AM</b>
Michael thanked the group for their ongoing participation in this process and wished them the best.			